

# Spiritual and Existential Distress

...

a literary and meditative tour through the minimal data pertaining  
to psychiatry in end of life care

# Instructions or rather examples of how to be afraid

In a small town in Scotland they sell books with one blank page hidden someplace in the volume. If the reader opens to that page and it's three o'clock in the afternoon, he dies.

In the Piazza Quirinal in Rome, there is one spot, unknown even to the initiated after the nineteenth century, from which, under a full moon, the statues of the Dioscuri can be seen to move, fighting against their horses as they rear back.

At Amalfi, where the seacoast ends, there's a jetty which stretches out into the sea and night. Out beyond the last lighthouse, you can hear a dog bark.

A man is squeezing toothpaste onto his brush, all of a sudden he sees the tiny figure of a woman lying on her back, coral sort of, or a breadcrumb that's been painted.

Opening the door of the wardrobe to take out a shirt, an old almanac falls out which comes apart immediately, pages falling out and crumbling and covers the white linen with millions of dirty paper butterflies.

There was a story about this traveling salesman whose left wrist began to hurt him, just under his wrist watch. When he removed the watch, blood spurted out. The wound showed the imprints of very tiny teeth.

The doctor finishes his examination and his conclusions are very reassuring to us. His cordial and somber voice precedes the medicines, prescriptions for which he is writing out at the moment, seated behind his desk. Every once in awhile he raises his head and smiles, to cheer us up. We don't have a thing to worry about, we'll be better inside of a week. We sit at ease in our easy chair, happy, and look idly and distractedly about the room. In the shadowed area beneath the desk, suddenly we see the doctor's legs. The trousers are pulled up to just above the knees and he's wearing women's stockings. - Julio Cortazar, 1965, *The Instruction Manual*

# Reddit thread Oct 15: redditors who know how much time they have left - how does your day look like? -

submitted 1 month ago by tidder 212

## Reddit thread Oct 15: redditors who know how much time they have left - how does your day look like? - submitted 1 month ago by tidder 212

“This is my time, and it took me a lot of dying before I could take a deep breath and let go of the stress of living. Sometimes the best thing for me to do is crack a beer and watch some TV and not feel guilty...if I’m happy, I’m happy.”

“What’s my day like? 100% normal, unless it isn’t.”

“It’s weird, living on borrowed time. It’s weird because it’s pretty normal.”

## Reddit thread Oct 15: redditors who know how much time they have left - how does your day look like? - submitted 1 month ago by tidder 212

“not really enough strength and energy to eat, though I am being yelled at for losing weight.... I have t-rex arms now, probably won't be able to walk or stand in the next few weeks...this is not how I want to live, have had time to get my affairs in order, but this sucks...I don't want to live like this anymore.” - lilblackhorse, 53 yo woman ALS rapidly progressing

“I just can’t see the upside in this,’ I heard myself say by way of explanation.

Later he said that if John had been sitting in the office he would have found this funny, as he himself had found it. ‘Of course I knew what you meant to say and John would have known too, you meant to say you couldn’t see the light at the end of the tunnel.’

I agreed, but this was not in fact the case.

I had meant pretty much exactly what I said: I couldn’t see the upside in this.”

- Joan Didion, *a year of magical thinking*, 2005.

## DDx:

Grief/complicated grief

Depression

Generalized Anxiety Disorder

Adjustment disorder with anxiety

PTSD

Panic disorder

Spiritual Distress

# Spiritual Distress

existential concerns	Lack of meaning Questions meaning about one's own existence Concern about afterlife Questions the meaning of suffering Seeks spiritual assistance	"My life is meaningless." "I feel useless."
Abandonment by God or others	Lack of love, loneliness Not being remembered No sense of relatedness	"God has abandoned me." "No one comes by anymore." "I am so alone."
Anger at God or others	Displaces anger toward religious representatives or others Inability to forgive	"Why would God take my child...it's not fair."
Concerns about relationship with deity	Desires closeness to God, deepening relationship	"I want to have a deeper relationship with God." "I want to understand my spirituality more."
Conflicted or challenged belief systems	Verbalizes inner conflicts or questions about beliefs of faith Conflicts between religious beliefs and recommended treatments Questions moral or ethical implications of therapeutic regimen Expresses concern with life/death or belief system	"I am not sure if God is with me anymore." "I question all that I used to hold as meaningful."
Despair/hopelessness	Hopelessness about future health, life Despair as absolute hopelessness No hope for value of life	"Life is being cut short." "There is nothing left for me to live for."
Grief/loss	The feeling and process associated with the loss of a person, health, relationship	"I miss my loved one so much." "I wish I could run again."
Guilt/shame	Feeling that one has done something wrong or evil Feeling that one is bad or evil	"I do not deserve to die pain free."
Reconciliation	Need for forgiveness or reconciliation from self or others	"I need to be forgiven for what I did." "I would like my wife to forgive me."
Isolation	Separated from religious community or other community	"Since moving to the assisted living, I am not able to go to my church anymore." "I have moved and no longer can go to my usual 12-step meeting."
Religious specific	Ritual needs Unable to perform usual religious practices	"I just can't pray anymore."
Religious/spiritual struggle	Loss of faith or meaning Religious or spiritual beliefs or community not helping with coping	"What if all that I believe is not true?"



## Lines Composed a Few Miles above Tintern Abbey, On Revisiting the Banks of the Wye during a Tour. July 13, 1798

I came among these hills...more like a man  
Flying from something that he dreads, than one  
Who sought the thing he loved...  
for such loss, I would believe,  
Abundant recompense. For I have learned  
To look on nature, not as in the hour  
Of thoughtless youth; but hearing oftentimes  
The still sad music of humanity...of ample power  
To chasten and subdue

- William Wordsworth

# Instructions on how to cry

Putting the reasons for crying aside for the moment, we might concentrate on the correct way to cry, which, be it understood, means a weeping that doesn't turn into a big commotion nor proves an affront to the smile with its parallel and dull similarity. The average, everyday weeping consists of a general contraction of the face and a spasmodic sound accompanied by tears and mucus, this last toward the end, since the cry ends at the point when one energetically blows one's nose.

In order to cry, steer the imagination toward yourself, and if this proves impossible owing to having contracted the habit of believing in the exterior world, think of a duck covered with ants or of those gulfs in the Strait of Magellan *into which no one sails ever*.

Coming to the weeping itself, cover the face decorously, using both hands, palms inward. Children are to cry with the sleeve of the dress or shirt pressed against the face, preferably in a corner of the room. Average duration of the cry, three minutes. - Julio Cortazar, *the instruction manual*, 1965

# Who is at risk? (a gross oversimplification)

Of the total number of participants, 74% reported accepting their situation and 8.6% reported accepting with "moderate" to "extreme" difficulty. More participants with acceptance difficulties than without acceptance difficulties met diagnostic criteria for a depressive or anxiety disorder ( $\chi^2(2) = 8.67$ ;  $P < .01$ ).

- Nonacceptors were younger ( $t = 4.13$ ;  $P < .000$ ),
- had more than high school education ( $\chi^2(2) = 4.69$ ;  $P < .05$ ),
- and had smaller social networks ( $t = 2.53$ ;  $P < .05$ ) than Acceptors.

Of the Nonacceptors, 42% described their experience as one of "moderate" to "extreme" suffering compared with 24.1% of Acceptors ( $\chi^2(2) = 5.28$ ;  $P < .05$ ). More than one third (37.5%) of Nonacceptors reported feeling hopeless compared with 8.6% who had no difficulty accepting ( $\chi^2(2) = 24.76$ ;  $P < .000$ ).

# Burden:Disease ratio

Known: sense of burden to others and marked end of life distress are linked

211 patients with end stage cancer

Most highly correlated variables with sense of burden to others

- depression
- hopelessness
- current quality of life
- level of fatigue

**No degree of association between sense of burden to others and actual degree of physical dependency, suggesting that this perception is mediated via psychological and existential considerations.**

# The psychedelic mystical experience in the human encounter with death

“With cancer patients the usual downhill course also involves an increase in pain and suffering. When this is treated with increasing doses of narcotic pain-killing drugs, there is increased clouding of consciousness. Aldous Huxley in his last novel, *Island*, describes the all too common situation for the dying cancer patient as increasing pain, increasing anxiety, increasing morphine, increasing addiction, increasing demandingness, with the ultimate disintegration of personality and loss of opportunity to die with dignity. To this list I would add psychological isolation, withdrawal, and depression.” - Walter Pahnke, The Ingersoll Lecture on Immortality, Harvard Divinity School, June 12, 1968

“People don’t realize how few tools we have in psychiatry to address existential distress. Xanax isn’t the answer. So how can we not explore this, if it can recalibrate how we die?” - Anthony Bossis, NYU psychiatrist

# Recalibrating how we die

- Physician Assisted Suicide - Oregon data/discussion/facilitated discussion regarding California
- Palliative sedation - briefly
- Psychedelics

# It can be totally reasonable to want to die

377 patients with cancer at 8 Canadian palliative care programs, desire for death rating scale.

- 69.5% no desire for death
- 18.3% occasional transient thoughts
- 12.2% genuine desire to die
  - of this subset, 52.2% with mental disorder such as depression or anxiety
  - 44.8% did not have a mental disorder

**~5% of your terminal patients will want to die and that is not indicative of another mental disorder.**



**Death with Dignity/Physician Assisted Suicide/Medical  
Aid in dying/Sanctioned Kevorkian-ism**

# Oregon

- law in 1994, into effect in 1997.
- total numbers (1997-2015): 1,327 people have received prescriptions, 859 have used these prescriptions for their own death. 31.0 DWDA deaths per 10,000 total deaths.
- no reports of ineffectual prescription usage
- median age: 71
- gender 47% male 53% female
- The three most frequently mentioned end-of-life concerns were: loss of autonomy (91.4%), decreasing ability to participate in activities that made life enjoyable (86.7%), and loss of dignity (71.4%)
- Average number of weeks of relationship between provider and patient: 19

# Debacles

Oregon health plan vs poor people

# Who asks?

Externally validated: PAD requesters had higher levels of depression, hopelessness, and dismissive attachment (attachment to others characterized by independence and self-reliance), and lower levels of spirituality.

Strong correlation between depression and hopelessness.

Self reported: The most important reasons for requesting PAD, were wanting to control the circumstances of death and die at home; loss of independence; and concerns about future pain, poor quality of life, and inability to care for one's self.

Lack of social support and depressed mood were rated as unimportant reasons for requesting PAD.

# Is death better?

There were differences reported in 9 of the 33 quality item indicators. Few significant differences were noted in items that measured domains of **connectedness, transcendence, and overall quality of death**. Those receiving PAD prescriptions had higher quality ratings on items measuring

- symptom control (e.g., control over surroundings and control of bowels/bladder)
- preparedness for death (saying goodbye to loved ones, and possession of a means to end life if desired) than those who did not pursue PAD or, in some cases, those who requested but did not receive a lethal prescription.

**89% die in their own home**

# For family?

A mean of 14 months after death, 11% of family members whose loved one requested aid in dying had major depressive disorder, 2% had prolonged grief, and 38% had received mental health care. **Among those whose family member requested aid in dying, whether or not the patient accessed a lethal prescription had no influence on subsequent depression, grief, or mental health services use; however, family members of Oregonians who received a lethal prescription were more likely to believe that their loved one's choices were honored and less likely to have regrets about how the loved one died...**Family members of Oregonians who requested aid in dying felt more prepared and accepting of the death than comparison family members. **In summary, pursuit of aid in dying does not have negative effects on surviving family members and may be associated with greater preparation and acceptance of death.**

## Briefly: California

“In 2009 California became the first state in the nation to pass legislation—the California law is called the Right to Know End-of-Life Options Act—requiring doctors and healthcare organizations to provide terminally ill patients with comprehensive information and counseling about their legal end-of-life care options. Even so, the law was watered down...Now the law merely allows doctors to give such information to patients who request it.” - Dr. David Muller, Health Care Policy

# I can't help you

Poor moth, I can't help you,

I can only turn out the light.

- Ryszgard Krynicki, 1943



## Briefly: California, continued

“I do not know what I would do if I were dying in prolonged and excruciating pain. I am certain, however, that it would be a comfort to be able to consider the options afforded by this bill. And I wouldn’t deny that right to others.” - Governor Brown, signing statement. Oct 5, 2015. *California End of Life Act*

## What to say?

“Charlie, it’s not uncommon for someone in your condition to think about wanting to control the circumstances of his own death. This might be something you’ll never have to deal with, but if it’s ever a concern, I hope you feel comfortable telling me about it. I’m comfortable discussing it, and there are actually a variety of things that can help.” - Dr. David Muller, Health Care Policy

“Allow Natural Death: AND” - Memorial Sloan Kettering protocol for code conversations

# Palliative Sedation

# Palliative Sedation: briefly

Some guidelines and recommendations identify existential suffering as a potential refractory symptom for which continuous palliative sedation (CPS) can be administered under certain conditions. However, there has been little research on the characteristics of patients with existential suffering treated with CPS and the degree to which the preconditions are fulfilled. The aim of this study was to provide insight into this specific indication for CPS. Questionnaires were sent to nursing home physicians in The Netherlands, who described 314 patients. Existential suffering was a refractory symptom in 83 of the patients. For most of the patients with refractory existential suffering, other refractory symptoms were also reported, and life expectancy was seven days or less; informed consent for initiating CPS had been obtained in all cases. Consultation and intermittent sedation before the start of CPS were far less frequently reported than one would expect based on the guidelines. Multivariate analysis showed that being male, having previously requested euthanasia, having a nervous system disease, or having an other diagnosis were positively correlated with the administration of CPS for existential suffering. We conclude that more attention should be paid to the suggested preconditions and to the presence of existential suffering in male patients or patients with a nervous system disease. - Journal of Palliative Care, 2015.

# The Well of Grief

Those who will not slip beneath  
the surface on the well of grief

turning downward through its black water  
to the place we cannot breathe

Will never know the source from which we drink  
the secret water, cold and clear

nor find in the darkness glimmering  
the small round coins  
thrown by those who wished for something else

- David Whyte

# The psychedelic mystical experience in the human encounter with death

At this point let us turn our attention to the question of why the psychedelic mystical experience seems to help these patients. I suggest that this experience has the potential for opening up the channels of positive feeling...deep within every human there are vast usually untapped resources of love, joy, and peace. One aspect of the mystical experience is a release of these positive feelings with subsequent decrease in negative feelings of depression, despair, and anxiety. This shift in mood is not enough to account for our most dramatic finding - loss of the fear of death....our data show that these feelings are released most fully when there is complete surrender to the ego-loss experience of positive ego transcendence, which is often experienced as a moment of death and rebirth....One patient, after his LSD experience, wondered how he could have been so worried about death, which now seemed to be just another step in the life process. Others frankly and calmly stated that they would be "ready to go" when the time to die came. This degree of acceptance and willingness to face the unknown was in strong contrast to the atmosphere of fear among the family and patient before psychedelic psychotherapy was started." - Walter Pahnke, The Ingersoll Lecture on Immortality, Harvard Divinity School, June 12, 1968

# Psychedelic experience:

- Psychotic
- cognitive
- aesthetic
- psychodynamic
- mystical

# Mystical experience

- Unity - cosmic oneness via ego transcendence. Consciousness or memory is not lost; person becomes aware of dimension vaster/greater than self.
- Transcendence of time and space
- Deeply felt positive mood - joy, blessedness, peace, love to overwhelming intensity
- sense of sacredness - awe and wonder
- Noetic Quality - William James: feeling of illumination that has certainty behind it
- paradoxicality: logical contradictions that make sense at the time
- Alleged ineffability - beyond words
- Transiency
- Persisting positive changes in attitude and behaviors.



# Schedule 1



# Mystical-type experiences occasioned by psilocybin mediate the attribution of personal meaning and spiritual significance 14 months later -

Roland Griffiths, MD psychiatrist, Johns Hopkins, 2008

Seven domains of mystical experience:

internal unity, external unity,  
transcendence of time and space,  
ineffability, paradoxicality, sense of  
sacredness, noetic quality, and deeply felt  
positive mood.

at 14 months:

58% most personally meaningful or top 5 most  
personally meaningful

67% most spiritually significant or top 5 most  
spiritually significant

64% indicate increased well being or life satisfaction

Innovations in research design - double blinded control  
for psychedelics.

Reliably catalyze mystical experiences leading to  
significant and lasting improvements in quality of life

22/36 fully achieved this (58%)

## Results continued...

“Completeness” of the mystical experience closely tracked the improvements in personal well-being, life satisfaction, and “positive behavior change” measured two months and then fourteen months after the session. - Michael Pollan, *The Trip Treatment*, The New Yorker. Feb 9 2015.

“I don’t want to use the word ‘mind-blowing’” Griffiths told me, “but as a scientific phenomenon, if you can create the conditions in which seventy per cent of people will say they have had one of the five most meaningful experiences of their lives? To a scientist, that’s just incredible.” - Roland Griffiths, as told to Michael Pollan, *The Trip Treatment*, The New Yorker. Feb 9 2015.

“The act that psychedelic research was being done at Hopkins - considered the premier medical center in the country - made it easier to get approved here. It was an amazing study, with such an elegant design.” - Anthony Bossis, NYU psychiatry, as told to Michael Pollan, *The Trip Treatment*, The New Yorker. Feb 9 2015.

# Pilot Study of psilocybin treatment for anxiety in patients with advanced stage cancer. - Charles Grob et al, Arch Gen psychiatry, 2011

- 12 patients + dx of (acute stress, GAD, anxiety due to cancer, adjustment disorder). 11 were women. 8 had hallucinogen experience >30 years ago.
- Met with staff, discussed study.
- Admitted, holter monitor, nice room, reviewed procedure.
- 2 weeks apart, double blinded, each subject acted as own control - psilocybin and placebo (niacin).
- 6 hours of monitoring

# Measuring

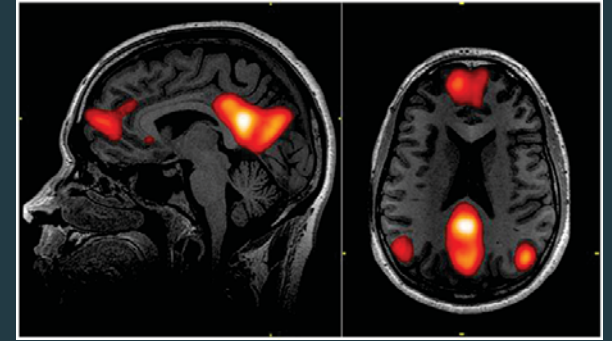
- Beck depression Inventory
- Profile of Mood States
- State-Trait Anxiety Inventory
- 5 Dimension Altered States of Consciousness profile (oceanic boundlessness, anxious ego dissolution, visionary restructuralization, auditory alterations, reduction of vigilance)
- Brief Psychiatric rating scale.

# Results

- 5 Dimension Altered States of Consciousness profile (oceanic boundlessness, anxious ego dissolution, visionary restructuralization, auditory alterations, reduction of vigilance)
  - psilocybin > placebo on oceanic boundlessness, visionary restructralization
- BDI scores
  - Psilocybin dropped scores almost 30% from first session to one month, sustained significance at 6 months
- Profile of Mood States
  - not altered at 6 months
- STAI
  - sustained decrease observed for the entire 6 month follow up. Significance achieved at one month and maintained.



# Psilocybin



- 5ht<sub>2D</sub> Serotonin agonist
- Decreases brain activity in the default-mode network, or **ego death**. **Experienced meditators have this area of their brain down-regulated.**
- Without the default mode, “regions that don’t ordinarily communicate directly with one another strike up conversations...hallucinations occur when the visual processing centers of the brain, become more susceptible to the influence of our beliefs and emotions.” - Michael Pollan, *The Trip Treatment*, The New Yorker. Feb 9 2015.

# The psychedelic mystical experience in the human encounter with death

Yet having passed through psychological ego death in the mystical experience, a person still preserves enough self-consciousness so that at least part of individual memory is not lost. In comparison, the loss of other attributes of individuality such as bodily sensations and personal ego accomplishments do not appear too important. It is at least suggestive that persons experiencing mystical consciousness do not feel that they have lost anything crucial - in fact, a common report is that they have come home and regained proper perspective. - Walter Pahnke, The Ingersoll Lecture on Immortality, Harvard Divinity School, June 12, 1968

“Tammy Burgess, given a diagnosis of ovarian cancer at fifty-five, found herself gazing across ‘the great plain of consciousness. It was very serene and beautiful. I felt alone but I could reach out and touch anyone I’d ever known. When my time came, that is where my life would go once it left me and that was okay.’

I was struck by how descriptions of psychedelic journeys differed from the typical accounts of dreams...They don’t regard these narratives as “just a dream”...but rather, as genuine and sturdy experiences. This is the “noetic quality” that students of mysticism often describe: the unmistakable sense that what has been learned or witnessed has the authority and the durability of objective truth...

This might help explain why so many cancer patients in the trials reported that their fear of death had lifted or at least abated: they had stared directly at death and come to know something about it, in a kind of dress rehearsal. ‘A high dose psychedelic experience is death practice,’ Katherine Maclean, the former Hopkins psychologist said. ‘You’re losing everything you know to be real, letting go of your ego and your body, and that process can feel like dying.’ - Michael Pollan, *The Trip Treatment*, The New Yorker. Feb 9 2015.

# Patrick Mettes, 54 yo, psilocybin trial participant at NYU

“In March, 2012, he stopped chemo....in April, his lungs failing, Mettes wound up back in the hospital. He gathered everyone together and said goodbye, and explained that this is how we wanted to die. He had a very conscious death.” - Michael Pollan, The Trip Treatment, *The New Yorker*, Feb 9, 2015.

# Other uses of psilocybin under consideration

OCD, smoking cessation, alcohol abuse, disorders of addiction

# Preamble for the instructions for how to wind a watch

Think of this: When they present you with a watch they are gifting you with a tiny flowering hell, a wreath of roses, a dungeon of air. They aren't simply wishing the watch on you, and many more, and we hope it will last you, it's a good brand, Swiss, seventeen rubies; they aren't just giving you this minute stonecutter which will bind you by the wrist and walk along with you. They are giving you—they don't know it, it's terrible that they don't know it—they are gifting you with a new, fragile, and precarious piece of yourself, something that's yours but not a part of your body, that you have to strap to your body like your belt, like a tiny, furious bit of some-thing hanging onto your wrist. They gift you with the job of having to wind it every day, an obligation to wind it, so that it goes on being a watch; they gift you with the obsession of looking into jewelry-shop windows to check the exact time, check the radio announcer, check the telephone service. They give you the gift of fear, some-one will steal it from you, it'll fall on the street and get broken. They give you the gift of your trademark and the assurance that it's a trademark better than the others, they gift you with the impulse to compare your watch with other watches. They aren't giving you a watch, you are the gift, they're giving you yourself for the watch's birthday. - Julio Cortazar, *the instruction manual*, 1965

# Instructions on how to wind a watch

Death stands there in the background, but don't be afraid. Hold the watch down with one hand, take the stem in two fingers, and rotate it smoothly. Now another installment of time opens, trees spread their leaves, boats run races, like a fan time continues filling with itself, and from that burgeon the air, the breezes of earth, the shadow of a woman, the sweet smell of bread.

What did you expect, what more do you want? Quickly. strap it to your wrist, let it tick away in freedom, imitate it greedily. Fear will rust all the rubies, everything that could happen to it and was forgotten is about to corrode the watch's veins, cankering the cold blood and its tiny rubies. And death is there in the background, we must run to arrive beforehand and understand it's already unimportant. - Julio Cortazar, *the instruction manual* 1965

J Pain Symptom Manage. 2015 Mar;49(3):555-61. doi: 10.1016/j.jpainsymman.2014.06.010. Epub 2014 Aug 10.

## Predictors of pursuit of physician-assisted death.

Smith KA<sup>1</sup>, Harvath TA<sup>2</sup>, Goy ER<sup>3</sup>, Ganzini L<sup>4</sup>.

J Palliat Med. 2011 Apr;14(4):445-50. doi: 10.1089/jpm.2010.0425. Epub 2011 Mar 18.

## Quality of death and dying in patients who request physician-assisted death.

Smith KA<sup>1</sup>, Goy ER, Harvath TA, Ganzini L.

<http://content.healthaffairs.org/content/31/10/2343.full>

J Clin Oncol. 2009 Dec 1;27(34):5757-62. doi: 10.1200/JCO.2009.22.9799. Epub 2009 Oct 13.

## Prognostic acceptance and the well-being of patients